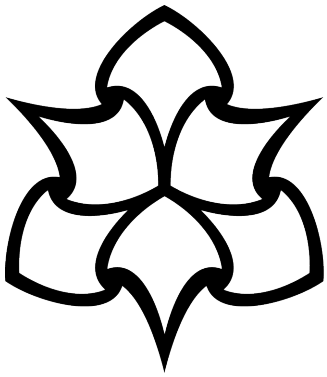

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ORIGINAL ARTICLE

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'If he feels better I'll feel better' relationships with individuals at high-risk of developing psychosis

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Abstract

Aim: A large proportion of individuals with an at-risk mental state (ARMS) live at home and are supported by their families. Recommended treatment includes family intervention (FI), and therefore, understanding relationships between individuals with an ARMS and their family members is key. This study aimed to provide a more holistic exploration of relationships within families of individuals with an ARMS by reporting the perceived impact of the condition on other family members including sibling and romantic relationships.

Method: Fourteen semi-structured interviews with family members were analysed using thematic analysis.

Results: Parents wanted to maintain a safe family environment for all family members. This can result in spending less time with siblings who impacted on siblings' relationships with the service user and other family members. Romantic relationships were negatively impacted when there was unclear communication between the couple, as well as the partner's response and understanding of the ARMS condition. Clear communication across sibling and romantic relationships facilitated helpful family/carer's behaviour and understanding of the individuals' mental distress.

Conclusion: FI should explore and support families with changes in sibling and romantic relationships. More research is needed to understand siblings' perspectives in families with individuals experiencing an ARMS and to develop resources to support partners and families in changes within their sexual and romantic relationships.

KEYWORDS
high-risk, psychosis, relationships, romantic, sibling

1 | INTRODUCTION

Individuals with an At-Risk Mental State (ARMS) are at high-risk of developing psychosis and experience high levels of distress and co-morbidity (Chang et al., 2020; Yung et al., 2005). The majority of people are supported by their families and in England, treatment recommendations for individuals with an ARMS includes family intervention (FI, NICE, 2014). Healthy relationships, with warmth and family involvement predicted increased social functioning and reductions in symptoms over time for individuals with an ARMS (Izon et al., 2018). Involving networks and families could help to reduce stigma and facilitate the engagement of individuals with an ARMS with mental health services (Ben-David et al., 2019; Izon et al., 2020).

Many caregivers experience positive effects of providing support and care, whilst simultaneously experiencing a strain on their own

health (Harmell et al., 2011). For example, caregivers of individuals with an ARMS experience mild–moderate symptoms of depression, distress and anxiety (Izon et al., 2018). Research involving caregivers typically explores the experiences of one parent (Smith et al., 2010). Sibling relationships are an important reciprocal relationship of long duration; often providing friendship, emotional and practical supports (Bank & Kahn, 2003). These relationships may be underutilized protective factors and bring positive outcomes. Siblings of individuals with early psychosis can also experience increased psychological distress, burden as well as changes in their functioning and relationships with both siblings and parents (Bowman et al., 2014). For siblings of individuals with an ARMS, their involvement and perspectives are yet to be explored.

The burden on relatives of individuals with psychosis has had increased interest over recent years, yet there is limited number of studies from the perspectives of spouses (Fitryasari et al., 2018). Research involving spouses of individuals with early psychosis report increased burden, distress, and problems with intimacy (Jungbauer et al., 2004). Considering that people with psychosis experience higher levels of loneliness compared to the general population (Chrostek et al., 2016), they may rely on their spouse's support, which puts pressure on their romantic relationship. Some individuals with an ARMS may live with their partners or access their support (Law et al., 2019; Meneghelli et al., 2011). The impact on the romantic relationships and experiences of partners of individuals with an ARMS are unknown.

The philosophical approach '*Critical Realism*' acknowledges the existence of an external world as well as a socially constructed world. It recognizes the existence of an individual and the role that their subjective interpretation plays in defining reality (O'Mahoney & Vincent, 2014). To take the research project forward an appropriate philosophical approach needs to be adopted to enable researcher flexibility to look at data from a subjectivist and positivist approach. Qualitative research can help to inform service delivery, which is relevant for the prevention and recovery among individuals at-risk of developing psychosis (Davidson et al., 2008). The authors are unaware of any study with family members or partners of individuals with an ARMS that explores themes around romantic and sibling relationships. The authors utilized the critical realist approach to explore relationships within families of individuals experiencing an ARMS and the perceived impact of the condition on other family members, including sibling and romantic relationships.

2 | METHODS

2.1 | Design

This study involved nominated family/carers from the Individual and Family Cognitive Behavioural Therapy trial (IFCBT, Law et al., 2019). This sub-study received ethical approval (reference: 16/NW/0278) during the final 6 months of recruitment for the trial.

2.2 | Sample

Eighteen family/carers were approached using convenience sampling, four declined to participate due to insufficient time or not wanting to be audio-recorded, therefore 14 interviews were conducted. Convenience sampling was the most time efficient method for the authors, with the first author recruiting for the IFCBT trial and conducting all the interviews. The current study's recruitment was forced to stop at 14 due to the end of recruitment for the trial.

2.3 | Procedure

2.3.1 | Pre-interview

The topic guide was developed alongside mental health professionals and experts by experience (both parents and service users). The topics included the family/carers' understanding of the ARMS, their relationship with the person and any challenges the family/carer may have experienced. The first author discussed the study with the family/carers over the phone and arranged the interview, which took place in person, typically at the family/carer's home. The interviews were arranged at convenient times for the interviewee, where they could allow an hour away from any other responsibilities, for example caregiving or work-related. Prior to their interview, the first author advised interviewees to inform other family members to prevent any disruptions and provided the option to re-arrange nearer the time.

2.3.2 | During the interview

Semi-structured interviews were conducted in a safe space with the door closed, to ensure privacy and confidentiality. Example questions were, '*what sort of challenges have you experienced?*', '*Please describe how you are feeling*', which enabled participants the space to discuss challenges within their specific relationship. Interview prompts aided the researcher, for example '*relationships with siblings or others*'. Interviews were audio recorded and lasted ~1 h. Participants were given £10 to thank them for participating.

2.3.3 | Post interview

The topic guide was adapted to include the family/carer's beliefs about challenges for other family members.

2.4 | Thematic analysis

The interviews were transcribed verbatim (including pauses, stutters and speech fillers). The interviews were transcribed by the first author and two other researchers. All the transcriptions were checked for accuracy by the first author, with two by another researcher and one

by co-author (P. F.). Transcriptions were input into NVivo11 qualitative analysis software. Analysis was guided by Braun and Clarke's (2006, 2019, 2020) six-phase process for data management, coding, and theme development in thematic analysis (TA). A latent, interpretive approach was adopted when undertaking the reflexive TA process, whereby coding and theme development were driven by assumptions and abstract concepts underpinning the data (Braun & Clarke, 2020). Line-by-line coding was conducted by the first author using a mixed deductive and inductive analytical process, which allowed theoretical assumptions to be interpreted from previous research and grounded from the data (Braun & Clarke, 2020). This complimented the philosophical critical realist approach, which allowed the authors to identify, explore and seek to understand participants' experiences, acknowledging the existence of an external world as well as a socially constructed world.

TA facilitated an in-depth understanding, whilst maintaining the flexibility of an approach when identifying patterns across the data. Initial team meetings focused around clustering of ideas from different transcripts and organizing codes into subthemes. The authors described the experiences of family/carers of individuals with an ARMS through qualitative description (Sandelowski, 2000), as opposed to, for example, phenomenological grounded theory description. The authors recognize that neither description nor analysis can be completely free of interpretation, but that answers to specific questions are more likely to result in easier consensus among researchers (Sandelowski, 2000; Sandelowski, 2010). Although methodological undertones involved qualitative description, the authors were continuously guided by TA. Refinement of themes and subthemes was ongoing, for example, three randomly selected interview were reviewed independently, to contribute an alternative perspective to the analysis (Braun & Clarke, 2019). Trustworthiness and credibility are pivotal tenets of rigorous qualitative research (Clarke & Braun, 2013). All authors discussed different ways of organizing the coding index and provided input regarding regular checking themes and development of the framework to enhance validity. The authors recognize that Braun and Clarke (2020) emphasize that there is no prescribed method of TA, but rather this should be driven by the nature of the data and theoretical methodology.

2.5 | Reflexivity

Reflexivity is important when conducting qualitative research for understanding the influence of the researchers' backgrounds and perspectives research (Malterud, 2001). For example, all authors are Caucasian and middle-class which may have influenced engagement with and understanding of family/carers of individuals experiencing an ARMS from other ethnic backgrounds and social groups. The first author's own positive experiences of family life and sibling relationships may have influenced her reasons for engaging additional family members and influenced the preliminary hypotheses of the benefits from involving others. During the early stages of data collection, the authors noticed patterns across the interviews surrounding the home environment and impact on other family members. The first author wrote her reflections from each interview, which included evoked feelings and thoughts. Feelings of responsibility in capturing the essence of these stories in the analysis and ensuring that the study findings were driven by the participants and not the author's feelings or beliefs. These reflections were used within the analysis process, to bring to the surface the subjectivity of the interviewer, for the team to maintain an objective research position. Bimonthly supervision helped to ensure that themes were clustered from the data as opposed to the authors' own opinions.

3 | RESULTS

3.1 | Participant characteristics

The 14 family/carers included nine mothers, four partners and one sibling. All the mothers (aged 41–56 years) lived with the service user: five had additional younger children living in the family home, one lived alone with the service user, and three had older children who no longer lived with the family. Of the mothers, five had separated from the service user's biological father. Four partners (aged 17–35 years) were involved in the current study, all of whom had a compassionate approach to mental health, which was grounded from their own personal experiences, a prior romantic relationship or from supporting others within a work capacity. Two of the four couples were cohabiting. Three couples had a relationship ranging from 1 to 5 years, whilst one couple had been together over 10 years. None of the couples had any children, but one was pregnant at the time of the interview. See Table 1 for demographic characteristics.

The impact of ARMS on sibling and romantic relationships were captured in two themes. The authors identified themes centred around mothers' beliefs that it was 'mayhem', with the ARMS condition and parental behaviours impacting on other siblings. Another theme related to the individual with an ARMS and their mental health 'taking its toll' on the romantic relationship. Clear communication across these themes facilitated a better understanding of the ARMS condition, the family/carer's behaviour and acceptance of change to the relationship with the at-risk individual.

3.1.1 | 'It was just mayhem for all of us'

Early psychosis literature typically focuses on females as the predominant caregivers (Cotton et al., 2013; Onwumere et al., 2020). In the current study, mothers were often providing sole care whilst working, managing the home, looking after other children and trying to access additional support for the individual with the ARMS. Mothers reported feeling stressed, and emotionally and physically exhausted. Mothers of school-aged children reported additional disruption at home when there was involvement of social services, for example regarding school attendance or safeguarding concerns. These mothers may experience feelings of shame, stigma and guilt from the

TABLE 1 Demographics of individuals with an at-risk mental state (ARMS) of psychosis and their family/carers

Variables of interest	Service user *N* = 14	Family/carer *N* = 14		
		Parent (*N* = 9)	Sibling (*N* = 1)	Partner (*N* = 4)
Age at entry				
Mean	21.15 (5)	49.22 (4.5)	31	24.75 (16.9)
Range (years)	17–34	41–56	–	17–35
Gender (*N*, %)				
Males	9 (64%)	–	–	1 (7%)
Females	5 (36%)	9 (64%)	1 (7%)	3 (21%)
Ethnicity (*N*, %)				
White British	12 (86%)	8 (57%)	1 (7%)	3 (21%)
White & Asian	1 (7%)	–	–	–
White & Black African	–	1 (7%)	–	–
Caribbean	1 (7%)	–	–	–
Any other mixed background	–	–	–	1 (7%)

Note: All data *N* (%) or mean (*SD*).

involvement of external services and feel increased stress on the impact for their other children.

> I was speaking to the school all the time and they were sending people round to try and get him to come into school and it was just mayhem for all of us. (Mum 5)

Parents reported feelings of guilt when they discussed their beliefs about other siblings' experiences at home. Mothers who had more than one child living at home provided less attention to the individual and reported that the time spent together was often of lower quality.

> The attention was obviously all on her and he (sibling) kind of got side-lined a little bit because we were so worried about, about her… it's-it's difficult to keep your eye on all of them and he seems quite ok so you're concentrating on the ones that aren't, so yeah it does unfortunately impact. (Mum 7)

To protect their other children, mothers' actions included providing vague information, withholding information or siblings temporarily staying with other family members. Siblings may experience changes to their relationship with their parent as well as changes to the relationship with their sibling. Unclear communication may lead to confusion, feelings of frustration and increased psychological distress for siblings.

> When I told [service user's older brother about her mental health], he was really shocked. And his attitude is a bit like 'what's wrong with her? She's got everything, what's wrong with her? She can do what she likes'. And I don't think he can see beyond that. (Mum 1)

Family members of individuals with an ARMS have reported a lack of understanding regarding the individual's symptoms, reduced motivation, and reduced functioning (Izon et al., 2019). Beliefs and understanding are often shared between family members (Onwumere et al., 2020), which may explain the shared initial understanding and similar emotional reactions that siblings and parents demonstrate. In contrast, some siblings may have even more knowledge about their sibling's mental health challenges than their parents, for example suicidal thoughts and behaviours (Dyregrov & Dyregrov, 2005). Parents recognized that their other children provided practical and emotional support to the individual with an ARMS.

> His brother does his best to support (individual with an ARMS). It can affect him, he become short tempered, perceives it as (them) getting special treatment. (Mum 5)

The age of the siblings, their psychological wellbeing, understanding of mental distress and parental open communication may impact siblings' beliefs, emotions, and behaviours towards caregiving. Some siblings can experience increased psychological distress (Bowman et al., 2014), whilst others may report positive associations of caregiving. The one sibling in the study reported warmth and positive feelings associated with providing support and companionship.

> I'm just dead proud of her… I see it as a mother daughter thing, even though she's not my daughter (Sibling)

3.1.2 | 'His mental health is taking its toll on their relationship'

The communication in a romantic relationship can help partners of individuals with an ARMS feel involved. Partners in relationships under 5 years discussed challenges and changes in communication in their romantic relationship. There was a feeling of loneliness and frustration expressed by partners who wanted to support the individual but did not know how and felt distant from their partner. This may have felt increasingly difficult for partners with their own personal experiences of mental health problems or prior experience supporting others.

> He just wants to try and get through [things] on his own, and that's very annoying, because you don't know what's going on. (Partner 3)

There is a challenge that couples face when one is forced to take on the more caring role in a partnership. Regardless of the length of the relationship, partners may feel injustice, shock and frustration towards their novel situation. Family/carer who felt despondent about the relationship with the individual also reported that the partner might feel unsupported and isolated in the relationship. It is understandable that romantic relationship breakdown follows early experiences of mental distress (Baker & Procter, 2015). Relationships that no longer provided reciprocal support, romantic satisfaction or intimacy were considered insufficient and unstable.

> It's not a romantic relationship at the minute at all. I think he's hopefully getting better now so, hopefully that will then improve our relationship as well, because if he feels better I'll feel better so [I] guess we [will] see what happens. (Partner 2)

> I know that his mental health condition is taking its toll and a strain on their relationship. I wouldn't blame his girlfriend if she decided that she'd had enough. (Mum 8)

The participant who was pregnant discussed childrearing and parental responsibility. They reflected on their childhood experiences and hopes from their partner. Partners of individuals with an ARMS may show empathy towards the person's emotional distress, however, with the addition of a child, the narrative may change. Partners may prioritize the baby and their pregnancy needs, which puts further strain on the romantic relationship.

> He knows that he's got me in his life. We going to have the baby in his life, and he needs to now step up… It can't just be me pulling all the weight. He's got to learn to pull the weight. (Partner 3)

In contrast, one partner reported how their open communication had continued. This couple lived together and were engaged compared with other partners in the study. Their relationships status may have impacted how they communicated clearly in their romantic relationships.

> We continue to support each other, and it just works really well. I think we have a good understanding of each other no matter the situation… [and] just talking more about things that we maybe didn't speak about so deeply before but because we need to, to sort things out, it's forced. (Partner 1)

4 | DISCUSSION

This study reported on the impact of the ARMS condition on sibling and romantic relationships, which have typically been neglected in previous literature. This study provided a holistic view of the family/carer experiences and impact within the home environment. It looked at the relationships of family/carers and factors that may influence and maintain sibling and romantic relationships Clear communication across these themes facilitated a better understanding of the ARMS condition, the family/carer's behaviour and acceptance of the relationship. These findings were shaped by the different ages and types of family/carers: mothers, partners and a sibling participating in the study.

We found parents were concerned about their other children receiving less attention at home and the impact on siblings' wellbeing. Siblings who feel ignored by parents, jealous of the sibling-parent relationship and lack the understanding of their brother or sister's mental distress may experience negative emotions towards their family relationships and negative outcomes on their health (Bowman et al., 2014). Siblings of individuals with an ARMS are important relationships to explore, as they too can provide friendship, emotional and practical support (Bank & Kahn, 2003). As mentioned previously, involving networks and families could help to reduce stigma and facilitate the engagement of individuals with an ARMS with mental health services (Ben-David et al., 2019; Izon et al., 2020). Siblings may be an underutilized positive protective factor for individuals with an ARMS. This interpersonal relationship has not been contextually compared to other sibling relationships, who may account for additional or contrasting experiences. Health professionals may need to discuss with parents the positive associations of sibling involvement and look to develop resources that further support siblings in their caregiving experiences.

Our findings that partners experience reduced intimacy and support in their romantic relationship is comparable to spouses of individuals with experiences of psychosis (Jungbauer et al., 2004). However, unlike the psychosis literature, partners of individuals with an ARMS were not married, younger and were not all cohabiting. We found that partners of individuals with an ARMS reported increased distress when they have reduced involvement, trust and clear communication in their romantic relationship, adding to the mental health literature. Previous research with family/carers of individuals with an ARMS suggests that family/carers can experience symptoms of depression and

anxiety in their carer role (Izon et al., 2018), which may be enhanced for partners who feel alone, guilt and experience new challenges in their romantic relationship. This may be particularly important for couples who are considering having children, where the needs of the child-bearer and baby create further changes to the relationship. Parental mental illness is often accompanied by many adversities that can impact on parenting and healthy child development (Wansink et al., 2014). In comparison to the general population, parents with a mental health problem have a higher likelihood of separation, divorce, and loss of custody of their children (Park et al., 2006). Healthcare professionals may need to provide more holistic support to individuals with an ARMS and their partners, which includes support in communication around managing their sexual and romantic relationship and conversations around family planning.

The existing literature is scarce around the experiences of partners and siblings. This study explored the family/carer perspective of the sibling and romantic relationships with an individual with an ARMS. Mothers expressed guilt and sadness wanting not able to support all their children and, in an attempt, to protect other children misinform or push away siblings. Some siblings may express shock from information that is difficult to comprehend, which may result in less supportive sibling relationships. In contrast, other siblings may provide support, warmth and companionship. Clear communication across sibling and romantic relationships facilitated helpful family/carer's behaviour and understanding of the individuals' mental distress. Partner's understanding of the ARMS condition and response towards changes in the relationship was important regardless of cohabitation or relationship length. These initial learnings are vital in acknowledging this disregarded group of family/carers and how services can help to provide holistic, person-centred support.

4.1 | Strengths and limitations

This is the first time anyone has attempted to explore the issues for siblings. Although the sample only included one sibling, other members of the family can reflect on issues that might impact on sibling relationships. Limitations aside, this study provides an initial exploration of this important topic that can be built on by future studies, for example sampling a larger and more heterogeneous sample of siblings of individuals with an ARMS. The authors recognize that participants' experiences might have also been influenced by the NHS and how western perspectives of mental health problems develop and are treated. The authors acknowledge that other patterns could have been observed, had recruitment been extended or conducted outside the single site trial exploring other siblings, romantic partners and family/carers perspectives. A purposeful recruitment method could have resulted in richer and more descriptive data. The term 'family/carer' was adopted to acknowledge family members who may or may not acknowledge themselves as a carer. The authors recognize the term may be perceived negatively by some service users and their families and that a better term may be needed.

4.2 | Clinical implications and future research

Addressing the experiences of family/carers has helped highlight their needs and changes to their romantic relationships and impacts on sibling relationships. It would be important to understand how healthcare professionals could provide support to family/carers to address needs in relation to wider family relationships. More open communication between family members, regarding how they feel about situations and spending time listening to one another, could enhance the quality of their relationship. Reflective practice facilitates communication, it provides an opportunity to grow, develop in understanding of the self, others, and different sensitive situations (Karnieli-Miller, 2020). Real time reflection can be difficult, and people need a safe space to practice (Misra-Hebert et al., 2012). Services could provide families with a space and opportunity to reflect together, facilitated by a therapist or healthcare professional.

Siblings may need support in managing the changes within their parental and sibling relationships. Partners of individuals with an ARMS may need support in understanding the changes and impact on their sexual and romantic relationships, as well as normalizing any negative feelings towards the relationship. Future qualitative research could explore the sibling experiences and quantitative research focus on the partner-service user romantic relationship and the resulting outcomes for both partners and levels of support within the relationship.

Future research should aim to involve more male partners, siblings and family/carers outside of a research trial. Continued research is needed to enhance services understanding of the needs and experiences of family/carers of different family backgrounds and cultures. This would help services to develop resources, identify training needs of staff and provide more holistic support to enrich unity and resilience within the family. Healthcare professionals themselves may benefit from reflective practice opportunities. This could enhance the service through greater emotional awareness (Walling et al., 2013), motivate additional learning (Grant et al., 2017) and provide patient and family specific information (Karnieli-Miller et al., 2020).

5 | CONCLUSION

Recommended intervention for individuals experiencing an ARMS can include FI (NICE, 2014), and therefore understanding and supporting other family members experiences is important. Evidence from this study suggest that sibling and romantic relationships are impacted by the ARMS condition and further considerations should be given to these relationships both within clinical practice and future research.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The data and materials that support the findings of this study are available from the corresponding author upon reasonable request. We have no conflict of interest to disclose.

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